



Published in final edited form as:

Prog Community Health Partnersh. 2012 ; 6(1): 33–41. doi:10.1353/cpr.2012.0008.

Improving Asian American, Native Hawaiian, and Pacific Islander Health: National Organizations Leading Community Research Initiatives

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Abstract

Background—Functionally, many CBPR projects operate through a model of academic partners providing research expertise and community partners playing a supporting role.

Objectives—To demonstrate how national umbrella organizations deeply rooted in communities, cognizant of community needs, and drawing on the insights and assets of community partners, can lead efforts to address health disparities affecting their constituents through research.

Methods—Case studies of two Asian American, Native Hawaiian, and Pacific Islander national organizations

Results—Strategically engaging a diverse range of partners and securing flexible funding mechanisms that support research were important facilitators. Main challenges included limited interest of local community organizations whose primary missions as service or health care providers may deprioritize research.

Conclusions—Efforts to make research relevant to the work of community partners and to instill the value of research in community partners, as well as flexible funding mechanisms, may help to promote community-driven research.

Keywords

Community-based participatory research; community health partnerships health disparities; health promotion; power sharing

Community-based participatory research (CBPR) is predicated on the collaboration between academic researchers and community partners with different but complementary roles and skills. Ideally, CBPR fosters co-learning between community and academic partners with the underlying ideology that “research knowledge” should not remain solely the domain of academic partners.^{1,2} Functionally, many CBPR projects operate through a model of academic partners providing research expertise and community partners offering contextually relevant recruitment strategies, access to populations, and input on issues of practical significance to the community. The assumed division of labor that pervades most CBPR literature is that academic partners lead the research process and community partners

play a supporting role. Only a limited number of studies³ cite strong examples of community partners leading the research process.

The purpose of this paper is to demonstrate how two national organizations rooted in Asian American (AA), Native Hawaiian (NH), and Pacific Islander (PI) communities and representing community concerns have taken initiatives in leading efforts to address health disparities affecting their constituents through research. Although they share the same overarching goal of improving the health and well-being of AAs and NHPs, the two organizations have employed distinct but complementary strategies pertaining to research and data. Partnerships with other stakeholders, such as federal agencies and academic and local community partners, have been critical in our efforts.

We describe common steps that each organization has taken to develop and implement research efforts with diverse focuses, barriers, and facilitators. We argue that our cases may represent a unique and emerging paradigm for CBPR, whereby nonacademic national organizations, in strong partnerships with local organizations, can lead research efforts. We also discuss the implications for other national and local organizations and suggest strategies that other community organizations may utilize in implementing a research agenda.

THE CASES: ASIAN AND PACIFIC ISLANDER AMERICAN HEALTH FORUM AND ASSOCIATION OF ASIAN PACIFIC COMMUNITY HEALTH ORGANIZATIONS

The Asian and Pacific Islander American Health Forum (APIAHF) influences policy, mobilizes communities, and strengthens programs and organizations to improve the health of AAs and NHPs. Through its national programs in community capacity building (Health Through Action [HTA] program), HIV, chronic diseases, domestic violence, and policy advocacy, APIAHF works with national networks of local AA and NHPI community-based organizations (CBOs) and other national organizations representing racial minorities. With some of these organizations (e.g., HTA partners), APIAHF formally acts as a funder and capacity builder; with others, such as policy advocacy organizations, APIAHF maintains relatively informal networks to collaborate with them on specific policy issues as needed. In addition, other APIAHF programs (such as HIV and chronic diseases) work with both formal and informal networks of organizations. APIAHF's research team includes two doctoral-level staff members and a research assistant.

The Association of Asian Pacific Community Health Organizations (AAPCHO) is a national member association of 29 CBOs dedicated to promoting advocacy, collaboration, and leadership to improve the health status and access of AAs and NHPs. The majority of AAPCHO's members are community health centers (CHCs) that provide culturally and linguistically appropriate health care to over 400,000 predominantly low-income and uninsured AA and NHPI patients, many of whom have limited English proficiency. AAPCHO's research team of five full-time staff includes a doctoral-level director of research, two masters-level research manager/associates, and two research assistants, as well as a half-time database programmer/analyst. Each staff works across research studies and interventions including in diabetes, cardiovascular disease, hepatitis, and cancer.

Historically, both AAPCHO and APIAHF emerged as direct responses to community concerns regarding the lack of concerted national AA and NHPI voices and efforts to address issues that affect the health of these communities.⁴ Working with key allies has been a core strategy for both organizations. APIAHF's focus has been on improving data and research on AA and NHPI health nationally by engaging government, academic, and local community partners. Working mostly with CHCs and other health care organizations, an

important focus of AAPCHO has been identifying the needs of underserved patients and developing data and research infrastructure to track and improve quality of care and services for them. APIAHF and AAPCHO have employed unique but complementary strategies in addressing the need for more research on AAs and NHPIs. Critical elements in the development of research initiatives include: 1) Identifying research needs; 2) improving data collection and reporting systems; 3) building internal and external capacity to conduct research; and 4) disseminating their work.

STRATEGIES TO LEAD RESEARCH EFFORTS FOR AA AND NHPI POPULATIONS

Identifying Research Needs

Identifying and addressing community needs has been noted as an important first step of action-oriented CBPR geared toward producing tangible outcomes.² In doing so, both APIAHF and AAPCHO have prioritized collaborating with a diversity of stakeholders and partners that will guide and provide input on the development and implementation of research initiatives.

Recognizing that the inadequacy of research and data itself is an important issue that has hindered efforts to address health disparities for AAs⁵ and NHPIs,⁶ APIAHF has made concerted efforts to address it in recent years, beginning with convening a series of national meetings attended by researchers, government officials, and community advocates.⁷⁻¹² Echoing those documented in the literature,^{13,14} issues identified in the meetings include small sample sizes that do not allow stable statistical estimates and the failure to disaggregate AAs by ethnicity in national health data, which masks greater health needs and disparities of smaller AA ethnic groups.⁷ Strategies to address these issues were also formed in these meetings, several of which guided APIAHF's subsequent work. As we discuss in the next section, APIAHF engaged a variety of partners in implementing some of these strategies, conducting advocacy targeting government agencies to address data systems issues and working with academic and community partners to improve data on AA and NHPI health.

AAPCHO has partnered with its member CHCs for over 25 years using a community-based participatory approach by integrally involving CHCs in identifying their provider and patient needs and to ensure that AAPCHO's programs are tailored to them. Using its guiding principles and direction from its National Research Advisory Committee composed of CHC staff, researchers, and advocates, AAPCHO operationalizes concepts often initiated by member CHCs while serving as the liaison to academic researchers who often contribute expertise in reviewing statistical analyses performed by AAPCHO, thus allowing AAPCHO to further build research capacity. Close collaborations with CHCs have given AAPCHO researchers unique insights that led to a variety of initiatives to improve understanding of the unique needs of underserved AAs and NHPIs and thus to advance the field. Most prominently, AAPCHO researchers developed a Medically Underserved AA and NHPI Communities' Index, consisting of population, poverty, limited English proficiency, and primary care to physician ratio indicators, to identify underserved areas not captured by existing federal indices for AAs and NHPIs nationwide.¹⁵ They also demonstrated the feasibility and need to include those culturally appropriate measures—most notably, limited English proficiency—in the federal designations of underserved areas,^{15,16} supporting advocacy with good science.

Because of the long-standing, collaborative relationships of both organizations with community and other partners, researchers at both organizations were cognizant of community research needs. However, because research is not the primary mission of either

organization and because resources required to conduct research projects are extensive, both organizations have experienced challenges in implementing research projects. For AAPCHO, conducting research involves time and resources for CHC staff at multiple health centers, which increases financial constraints and may be perceived by some staff as being at odds with their primary mission to provide patient care. APIAHF has been confronted with similar challenges in that the primary mission of its community partners is to provide services to more vulnerable members of their communities, not to conduct research. Also, the sheer scale and vast resources involved in conducting national research projects posed an inevitable obstacle for APIAHF in addressing the research needs identified.

To a certain degree, securing adequate and appropriate funding sources has helped both organizations to address these challenges. AAPCHO was awarded a large 3-year grant from the U.S. Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA), affording their health centers to expand their research departments and increasing comprehensive CHC engagement in research projects with a great potential to generate meaningful community benefits. A large 5-year grant from the W. K. Kellogg Foundation has allowed APIAHF to conduct its own secondary analysis projects using large national data and also to support research projects conducted by its local partners.

Improving Data Collection and Reporting Systems

To help improve national health data on AAs and NHPs, APIAHF has primarily relied on engaging federal government agencies (through advocacy) and academic partners. One of the public comments APIAHF submitted to federal agencies was to the Centers for Disease Control and Prevention National Center for Health Statistics (NCHS), calling for an oversampling of AAs in the National Health and Nutrition Examination Survey (NHANES). This comment helped to spur the NCHS's decision to oversample AAs in the 2011–2014 NHANES. APIAHF staff has been having regular telephone conferences with NHANES staff to provide community input in recruiting study participants and bilingual field interview staff, suggesting experts for cultural competency training for NHANES staff and field staff, and crafting culturally appropriate outreach materials.

The extent to which APIAHF is able to promote improved national data collection also depends on the willingness of key partners to do so. For example, APIAHF has also argued for oversampling of NHPs, whose even smaller sample sizes in national surveys result in estimates being underreported or not reported, to a greater degree than for AAs. However, the NCHS did not agree to oversample NHPs.

To help improve data on NHPs, APIAHF employed a different strategy, one that involves leveraging its network with academic researchers. APIAHF provided seed funding to an NHP researcher at the University of Michigan—a co-author of this article—who has since successfully secured federal funding to collect representative baseline NHP health data from 600 Samoan and Tongan adults and adolescents, achieving a sufficient sample size for stable estimates. This study, a project administered by researcher-trained local NHP community interviewers, is currently underway.

AAPCHO has worked primarily with its CHC network to develop and implement national health center data collection models in efforts to continually improve culturally appropriate care for medically underserved AAs and NHPs. For example, to help underserved patients access quality care, AAPCHO worked with CHCs, and academic and national partners on a project funded by DHHS Office of Minority Health to develop and implement a systematic data collection protocol to include enabling services (such as language interpretation and enrollment assistance in health insurance programs), to demonstrate to payers and

polymakers the value of these services and to advocate for their adequate reimbursement.¹⁷ AAPCHO has partnered with regional and national associations to disseminate the data collection model to CHCs nationwide to help build a momentum toward that goal. Challenges have included convincing partners of the importance of instituting a data collection system that will allow data disaggregated by ethnicity and comparable across CHCs; however, securing funding, as discussed, has helped to legitimize these efforts.

Research Capacity Building

Both APIAHF and AAPCHO have worked to build research capacity of their local partners. APIAHF developed a project in collaboration with the New York University Center for the Study of Asian American Health to create a research training curriculum for AA and NHPI community organizations.¹⁸ Working with the National Advisory Committee of community advocates it helped to assemble, APIAHF has provided input in each stage of the curriculum development process. Another program, HTA—APIAHF's flagship capacity-building program involving 18 community partners and coalitions in 15 states—has gone beyond the scope of conventional capacity building that focuses on organizational development and financial sustainability¹⁹ by making research training and technical assistance a high priority and by helping to improve community partners' understanding of the critical role data and research play in community education, policy advocacy, and other interventions. APIAHF has also supported local data collection by its partners. For example, APIAHF funded a local study to support an existing community-based needs assessment to include additional small ethnic groups in the sample. This project collected data in over a dozen Asian ethnic languages, reducing language-related barriers for study participants, an important methodological issue identified in research of populations with limited English proficiency.^{13,20}

APIAHF's other programs—most notably, HIV and domestic violence programs—have also worked to improve community research capacity. For example, in collaboration with the National Resource Center on Domestic Violence, the domestic violence program staff trained and guided CBOs serving Asian survivors of domestic violence to conduct surveys of their clients. The HIV Program provided capacity-building training to staff at seven CBOs to administer a survey as part of a study funded by the National Institutes of Health (NIH) on HIV testing among Asian men who have sex with men.²¹

AAPCHO is also increasingly developing research capacity and infrastructure at CHCs with every original research project undertaken. For example, working with member CHCs and health plans, AAPCHO developed an electronic health information exchange funded by the DHHS HRSA Office of Health Information Technology to share patient data and increase CHC capacity to track quality improvement. This intervention led to a demonstration project funded by Robert Wood Johnson Foundation to evaluate whether health plan incentives can improve patient outcomes and reduce costs. AAPCHO was also one of four recent health-center-controlled networks that received a Community Health Applied Research Network grant funded by the DHHS HRSA to build capacity and conduct patient-centered outcomes research with member CHCs, a rare opportunity to build a common research infrastructure at four CHC networks to conduct CBPR in underserved and underresearched communities.

Both APIAHF and AAPCHO have encountered challenges in their research capacity-building efforts. As discussed, a main challenge for both organizations included limited interest of local CBOs or CHCs, which, given their primary identity and duties as service providers, may deprioritize research. To stimulate the interest of local partners, APIAHF tries to provide more in-person research training sessions—deemed more conducive to learning of research skills than webinars. In addition, to make research training more

relevant to their day-to-day work as a service provider, APIAHF plans to communicate and teach user-friendly skills that may be useful for community organizations, such as focus groups and basic data analysis skills using accessible office software.

Dissemination

APIAHF and AAPCHO have prioritized dissemination to various audiences, an important aspect of CBPR,²² and have developed various products from their research initiatives. Both organizations are actively engaged in presenting research efforts and advocating for better data at local and national conferences and policymaking venues.^{12,23,24} APIAHF actively supported and also served as an editor for the first-ever special issue of the *American Journal of Public Health* published in May 2010 and devoted entirely to AA and NHPI health and health care issues to increase knowledge and awareness of them. Although an important accomplishment, publishing within an academic journal may limit dissemination to mostly academic researchers or public health professionals. To help community partners keep abreast of health issues affecting their constituents and socioeconomic and cultural conditions that may affect their health, APIAHF continues to analyze, compile, and disseminate available national data in the form of community briefs and reports. Similarly, AAPCHO has focused on developing reports specifically catered to the community audience and has published in local in-language community newspapers and media.^{25,26} APIAHF produced a comprehensive report on NHPI health²⁷ with input from NHPI community collaborators, as well as a series of briefs on the socioeconomic conditions of AAs and NHPIs,^{28,29} using Census and America Community Survey data. Findings reported in these reports will inform APIAHF's future advocacy, interventions, and research.

AAPCHO has collected, analyzed, and disseminated a wide range of data and resources on AA and NHPI health issues to inform CHC quality improvement and delivery practices, including an online CBPR toolkit,³⁰ online health data and literature database,³¹ and Geographic Information System maps identifying medically underserved AA and NHPI areas.³² AAPCHO has also published in the peer-reviewed literature with AAPCHO staff as the lead authors,¹⁵⁻¹⁷ and in recognizing the importance of disseminating research results back to the community, has also developed in-language materials (e.g., factsheets) for community members.³³ In an effort to better understand best practices in research dissemination, AAPCHO is collaborating with University of Washington in a project funded by the NIH National Cancer Institute to learn how to more effectively integrate research-tested interventions to CHCs in their future research.

AAPCHO's research efforts have also directly influenced policy and practice. For example, data collection and analysis of enabling services has improved CHC funding opportunities, improved health plan payment and allocation of appropriate interpretation services, and guided management decisions that brought health plan representatives onsite to assist with eligibility assistance for uninsured patients.³⁴ In collaboration with University of California Berkeley, AAPCHO's member center Asian Health Services, and a community advisory committee consisting of patients, family members, CHC staff, and other community advocates, AAPCHO evaluated a diabetes health coach intervention to help Chinese patients improve their care and outcomes. The successful implementation has led to dissemination of the model to include patients with other chronic care diagnoses and other sites within the CHC.

LESSONS LEARNED: BARRIERS, FACILITATORS, AND STRATEGIES

Because of the differences in their missions, structures, relationships with partners, and respective goals pertaining to research and data, APIAHF and AAPCHO took different but complementary approaches to implementing research agendas. We draw several lessons

from the case studies of these two organizations that may be broadly applicable to other CBOs at various levels, as well as to the field of CBPR.

First, strong partnerships are critical in facilitating community-driven research, as most CBOs may lack sufficient resources to conduct research independently. Both APIAHF and AAPCHO work with a wide range of partners nationwide, which they have leveraged to identify and address research needs unique to their communities. APIAHF has engaged a federal agency, academic researchers, and community partners to improve national and local data on the health of their constituents. AAPCHO has worked closely with its member CHCs and academic researchers to conduct its own research projects, serving as a model for collecting appropriate community data and building infrastructure for better data collection. Partnerships between communities and government agencies in CBPR have been reported,^{3,35-38} but the case studies of APIAHF and AAPCHO reveal unique partnerships that have not been reported previously. APIAHF's case illustrates, most prominently, how a national umbrella organization can help to shape the way in which government agencies collect data on communities. AAPCHO's experience demonstrates how another national organization can work closely with its local partners to conduct research geared toward informing policy and practice.

Second, strong support from the leadership with keen recognition of the strategic value of research and data was among the most critical facilitators of community-driven research and related advocacy. AAPCHO's board of directors, composed mostly of CHC executives, has strongly endorsed the organization's research efforts with an understanding that their clientele (which are mostly disadvantaged community members) would ultimately benefit from such efforts. APIAHF's trained academic researchers have served as or worked closely with the organization's leadership to spearhead national advocacy and promote local efforts to improve research and data on AAs and NHPs.

Third, the perception of research as incompatible or secondary to the core missions of local CBOs or CHCs was an important obstacle to CBPR. To address these challenges, making research relevant to the day-to-day work of CBOs—for example, reminding them of its utility in evaluating and demonstrating the needs of their constituents or to promote community-level change—has been a recent focus of APIAHF research staff working closely with community partners. For AAPCHO, prioritizing research that has immediate benefits for patients—for example, evaluation of an electronic clinical decision tool to identify patients deficient in preventative visits or screenings and a health coach intervention model to improve diabetes care—and securing research funding sources that also support direct services is important to address these challenges. Integrating research into their health centers' current workflow patterns to have minimal effect on patient care has also been an important facilitator. Concerted efforts should be made to make research relevant or directly beneficial to communities and to get buy-ins from the organizational leadership.

Fourth, both organizations have experienced resource-related barriers in implementing their research agendas. Although they have been successful in securing both federal and private funding to support their research initiatives, it has been challenging to identify adequate and sustainable funding to support their unique research programs. Government funding agencies and private foundations may help to legitimize and promote research initiated by community organizations by providing funding for such purposes. Limitations of current funding mechanisms that may not be conducive to supporting CBPR have been widely documented.³⁹ In addition, many federal research funding opportunities such as most NIH funding mechanisms require that an academic partner serve as the principal investigator, which makes it difficult for CBOs to advance their own research agendas. Although rare, there are flexible funding mechanisms that allow community research capacity building,

including those provided by private foundations (e.g., W. K. Kellogg Foundation support of APIAHF's HTA program and Robert Wood Johnson Foundation support of AAPCHO's Pay-for-Performance project). The DHHS HRSA's recent Community Health Applied Research Network program also serves as an ideal model; it is the first-ever opportunity to build research capacity exclusively at CHCs. Additional funding mechanisms like these should be created to legitimize community-driven research and build capacity across CBOs in a truly empowering manner.

We have demonstrated how two national organizations, deeply rooted in communities, well-cognizant of community concerns, and drawing on the insights and assets of community partners, can conduct truly "community-based" research to advance good science and inform policy. Our case studies point to a new type of CBPR partnership, one between local community partners and national umbrella organizations. Uniquely positioned to bridge research and practice, research staff working for the latter have served in a hybrid researcher–community capacity, facilitating internal organizational buy-in into the importance of research and further leveraging of external partners to improve research and data on their constituencies. To help fulfill CBPR's promise to integrate research and action to improve the health and well-being of disadvantaged communities,^{40,41} these national and local collaborations need to be fostered. We also noted the obstacles posed for CBOs in conducting CBPR, such as limited resources and their primary missions, which may seem incompatible with research. Making research more relevant to CBOs and their constituents is critical to make community participation genuine and meaningful. Further efforts to understand the unique challenges and facilitators to community-initiated and community-driven research can advance the field of CBPR, and ultimately, provide foundational models to improve the health of communities.

Acknowledgments

The authors acknowledge the support of our numerous community, academic, and government partners that helped identify critical needs related to data and research on AA and NHPI health and other community needs and that collaborated with us in efforts to address them. We also acknowledge the generous support of our funders. APIAHF's work was supported by the W. K. Kellogg Foundation through the Health through Action Program, the Centers for Disease Control and Prevention (CDC) Capacity Building Program 05055 (U50/CCU925132), and National Institute for Minority Health and Health Disparities grant P60 MD000538-07S1. AAPCHO's work was supported by DHHS HRSA, Robert Wood Johnson Foundation, NIH National Institute of Nursing Research, and NIH National Cancer Institute, and the California Endowment. We thank Ed Tepporn, HIV Program Director of APIAHF, and Chic Dabby, Director of API Institute on Domestic Violence, for having provided information on their CBPR capacity building work. We are grateful to the Centers for Disease Control and Prevention NCHS staff, particularly Lisa Broitman, who has reviewed the manuscript and provided comments. Dr. Islam's time to contribute to this manuscript has been supported through grants: P60MD000538-02, U58DP001022-01, R24001786-01, U48DP001904-01 and 1UL1RR029893. We also thank Stacy Lavilla, Director of Communications, Hui Song, Research Manager, and Heather Law, Research Associate, all of whom are affiliated with AAPCHO, for reviewing manuscript drafts and contributing to the success of AAPCHO's research programs. Last, we thank Dr. Winston Tseng of University of California Berkeley, Health Research for Action and APIAHF for his contribution to APIAHF's research program and feedback on the manuscript. The contents of the manuscript are solely the responsibility of the authors and do not necessarily represent the official views of funding agencies.

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